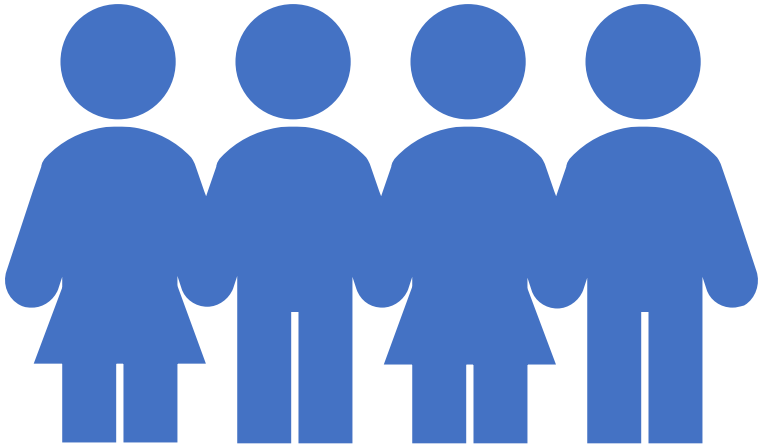

Transitioning the child with IBD into your adult practice

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Digestive Diseases at the Caribbean 2022

Disclosures

Research grants to the University of Puerto Rico

- AbbVie
- BMS
- Tigenix

Educational grants to the University of Puerto Rico

- AbbVie

Audience poll

How many of you treat adults with IBD? Adolescents? Both?

How many have a transition protocol or arrangements with GI Ped?

How many are just direct transfers Peds to Adult?

- **Is this satisfactory?**

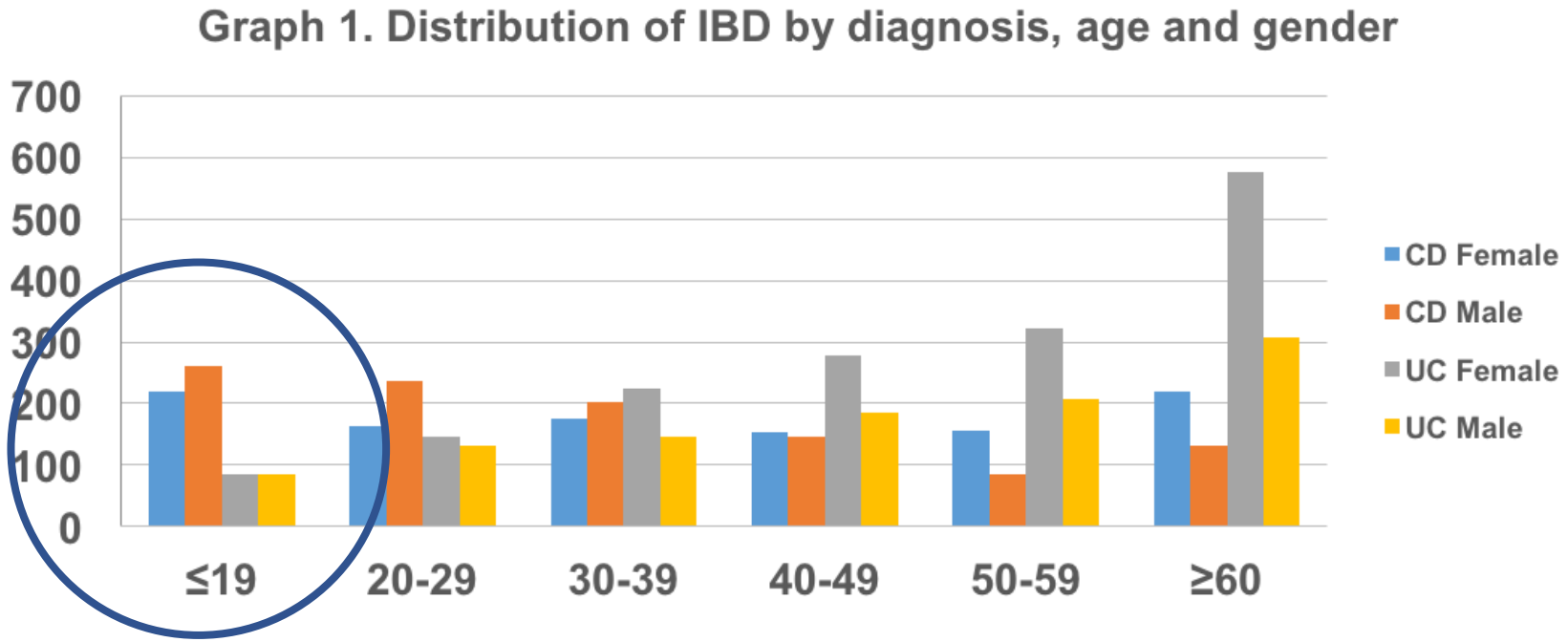
Encuesta Transición de Servicios de Salud Pediátricos a Servicios de Adultos

Why should we care?

Pediatric IBD increasing globally

- Canada 38.2/100,000 prev 2010
- Scotland 76% increase in prevalence from 1990-95 to 2003-08
- France 1998-2007 incidence 20-30/100,000

- **Puerto Rico** prevalence 2013
  - CD 59.97/100,000
  - UC 21.11/100,000
  - **3X increase from 2005**



Children are NOT small adults

Pediatric IBD

- More extensive and severe disease
- Crohn's > UC
- Interferes with growth, education, employment, psychosocial and sexual development
- These children will become adults with IBD
- Health systems are not ready for them
- Structured IBD transition process is in infancy

Adolescents with IBD

Poorer QoL than healthy peers

- intrusive gastrointestinal symptoms
- corticosteroid exposure
- release of centrally active pro-inflammatory cytokines

Higher prevalence of psychological distress

- in particular depression

Other differences

Comparative studies between children and adults in IBD have not been undertaken

- it seems likely, given the extent and inflammatory nature of their disease, that adolescents will suffer more

Avoidant coping is more commonly employed by adolescents with IBD than their peers

- individuals distract themselves with social diversion to deal with stress

Adolescents vs adults

Complex and extensive disease

Often with ongoing active inflammation refractory to medical treatments

Not easily amenable to surgery

Complicated by growth failure and significant psychological distress

Risks and benefits of individual therapeutic strategies differ

- hepatosplenic T cell lymphoma (IMM)
- fertility and fecundity

Traditional adult services are not well suited to serve this complex group

Transition from child to adult care

Planned purposeful transfer of adolescents and young adults from child centered healthcare to an adult-oriented one

Gradual changes in knowledge, attitudes and behavior

Prepared to be responsible for their health

Transfer to a life-long physician

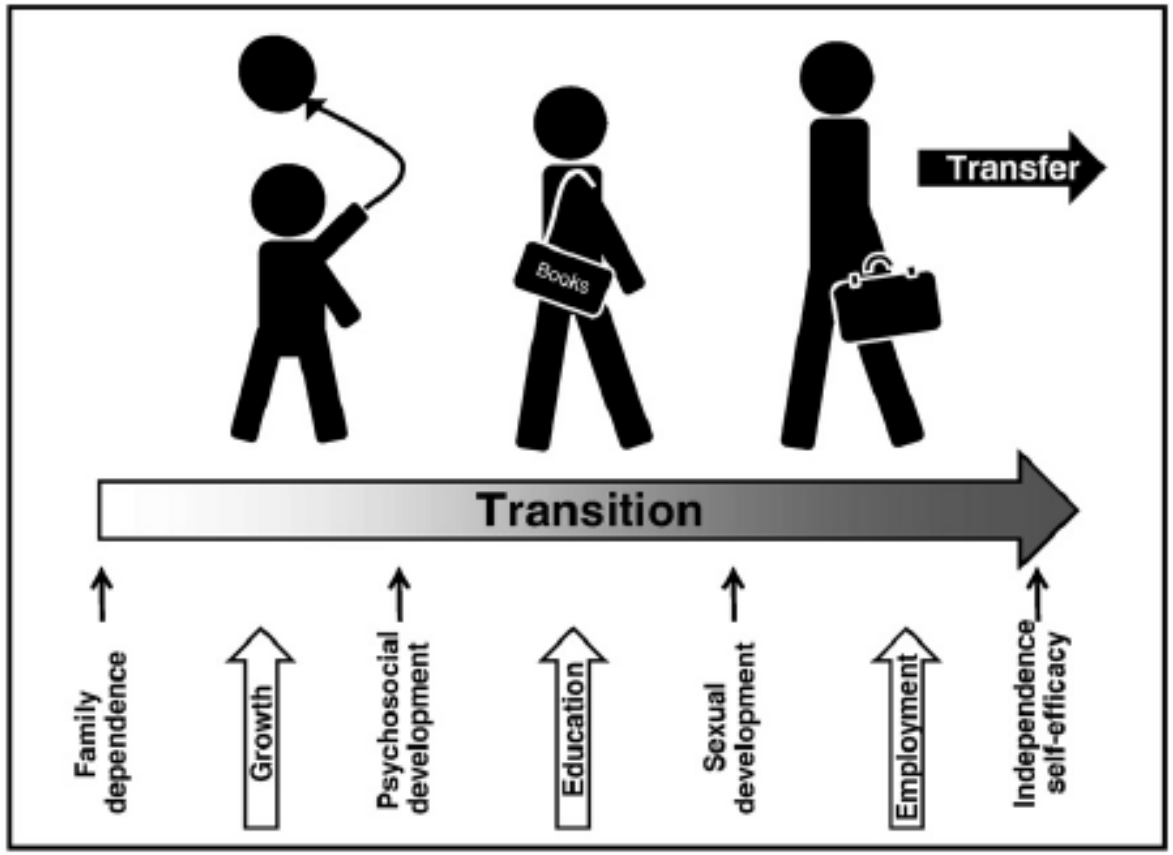


Figure 1 Adolescent milestones, transition and transfer of care. A schematic diagram that demonstrates the differences between transition and transfer with the milestones that patients may be expected to reach at each stage.

Goodhand J. JCC 2011;5:509-19

Transition aims

To educate the patient and their parents so that they are ready for transfer to adult services

To ensure that the receiving healthcare provider is sufficiently informed about past and current problems so as to provide continuity of care

An inadequate transition process results in:

- delayed and inappropriate care
- improper timing of transfer
- undue emotional and often financial stress for patients, families, and the healthcare system

Risks in transition of care

- Decrease in treament adherence
- Loss of medical information
- Lost to follow-up
- Transition from multidisciplinary to individual care

Medication adherence

- Complex and poorly understood
- Time constraints
- Medication side effects
- Poorly controlled disease activity
- Perception that the drug is not working
- Simply forgetting

Adolescents with IBD: The importance of structured transition care. J. Goodhand et al. Jour Crohn's Colitis (2011) 5, 509–519

Good adherence predictors

- Shorter disease duration
- Greater maternal involvement in the medical regimen
- Higher perceived disease severity

Pediatric vs adult clinics

Pediatric clinics

- Family-focused
- Appointments more frequent and longer
- Multidisciplinary approach, including specialist nurses, dieticians, clinical psychologists, pharmacists and the medical team

Adult clinics

- Individual, direct to patient
- Shorter focused appointments, longer follow-up intervals
- Multidisciplinary care usually limited to specialized IBD centers

Guiding the transitioning child: their tasks

Know their disease: diagnosis, extent
Learn to explain their symptoms- practice
Understand what studies have been done and what they are for
Know medications and dosages
Was surgery for IBD performed? Which and why?
Talk to their doctor, ask questions, share their worries

Guiding the transitioning child: their tasks

Discuss the role of their family, teachers, peer groups and themselves in their care

Consider the impact of their disease on school attendance and academic aspirations

Adolescents with IBD: The importance of structured transition care. Goodhand. Jour Crohn's Colitis (2011) 5, 509–519

Guiding the transitioning child: their tasks

- Capable of making informed therapeutic decisions
- Book and attend appointments and investigations
- Maintain an awareness of their sexual fecundity and the need for contraception
- Plan ahead and use the service in a flexible way

Reluctance of all

Pediatric caregivers are often reluctant to relinquish their patient's care

- about a third of pediatric diabetes centers and cystic fibrosis units continue care for patients over 25

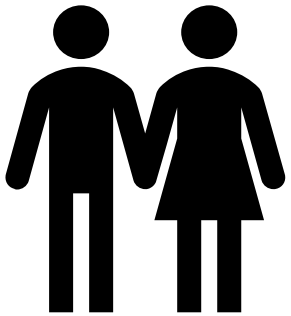
Qualitative data suggest that children and their parents are frequently reluctant to break the familiar relationship with their pediatrician who they have often known since diagnosis

- anxiety about joining a new healthcare team that is not appropriately informed of their history

Structural and cultural differences

+

Differences in approach, organization and practice management



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Reluctance to engage in transition

BUT.....

One qualitative theme identified in several studies was that teenagers like being treated as adults and prefer healthcare staff to address them instead of their parents.

In this young age group few adult or pediatric gastroenterologists directly address the issues of social drug use or safe sex.

Data from transplant recipients suggest that teenagers would value this information though they do not want to ask directly for it.

Table 2 Adolescent and disease specific milestones that determine the 'ideal' timing of transfer to adult care.

Determinant	Ideal
Chronological age	Between 16 and 25
Maturity	Mature (role self-efficacy scales)
Independent in health care	No longer reliant on parents
Self-advocacy	Ability to make informed decisions
Preparation	Knowledgeable
Readiness	Comfortable with adult care team
Availability of adult specialist	Specialist interest in adolescent IBD
Current medical status	Clinical remission
Adherence to treatment	Adherent even in remission

Goodhand J. JCC 2011;5:509-19

When:

- Ensure the transition planning is developmentally appropriate and takes into account each young person's capabilities, needs and hopes for the future
- The point of transfer should:
  - not be based on a rigid age threshold
  - take place at a time of relative stability for the young person

How? Facilitating the transition

Choose an expert in IBD

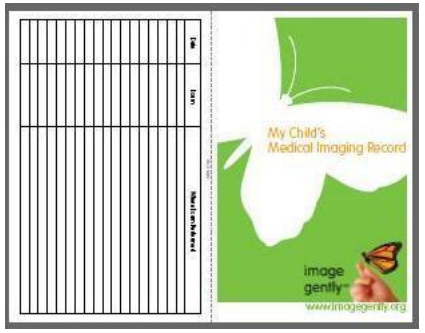
Discuss the transition

concurrent visits, treament plans

Explain to the patient what to expect and how pediatric and adult medical care differs

Encourage patient to come alone to pediatric visits, manage appointments, know the staff, be able to contact MD in an emergency, and learn how to use health insurance

A single one-hour joint clinic where pediatricians introduce the adolescent to the adult team and handover care in detail is sufficient with 85% patients and 74% parents reporting being ready to transfer



My IBD Manager from AGA
The AGA's app for IBD patients
@Point of Care
Free

Empower the patient!

Models

‘The Good 2 Go Transition Program’ established at the Hospital for Sick Children (SickKids) in Toronto

MyHealth passport

Handheld synopsis of their condition, developed for adolescents.	This simple card details the pertinent IBD history and fits into a wallet

Healthcare Provider Transitioning Checklist

AGE	PATIENT	HEALTH CARE TEAM
12-14	**EARLY ADOLESCENCE** *New knowledge and responsibilities* ☐ I can describe my GI condition ☐ I can name my medications, the amount and times I take them ☐ I can describe the common side effects of my medications ☐ I know my doctors' and nurses' names and roles ☐ I can use and read a thermometer ☐ I can answer at least 1 question during my health care visit ☐ I can manage my regular medical tasks at school ☐ I can call my doctor's office to make or change an appointment ☐ I can describe how my GI condition affects me on a daily basis	☐ Discuss the idea of visiting the office without parents or guardians in the future ☐ Encourage independence by performing part of the exam with the parents or guardians out of the examining room ☐ Begin to provide information about drugs, alcohol, sexuality and fitness ☐ Establish specific self-management goals during office visit
14-17	**MID ADOLESCENCE** *Building knowledge and practicing independence* ☐ I know the names and purposes of the tests that are done ☐ I know what can trigger a flare of my disease ☐ I know my medical history ☐ I know if I need to transition to an adult gastroenterologist ☐ I reorder my medications and call my doctor for refills ☐ I answer many questions during a health care visit ☐ I spend most of my time alone with the doctor during visit ☐ I understand the risk of medical nonadherence ☐ I understand the impact of drugs and alcohol on my condition ☐ I understand the impact of my GI condition on my sexuality	☐ Always focus on the patient instead of the parents or guardians when providing any explanations and ☐ Allow the patient to select when the parent or guardian is in the room for the exam ☐ Inform the patient of what the parent or guardian must legally be informed about with regards to the patient condition ☐ Discuss the importance of preparing the patient for independent status with the parents or guardian and address any anxiety they may have ☐ Continue to set specific goals which should include: • Filling prescriptions and scheduling appointments • Keeping a list of medications and medical team contact information in wallet and backpack **DISCUSS IN MORE DEPTH:** ☐ The impact of drugs, alcohol and non adherence on their disease ☐ The impact of their disease on sexuality, fertility ☐ Future plans for school/work and impact on health care including insurance coverage. ☐ How eventual transfer of care to an adult gastroenterologist will coordinate with future school or employment plans
17+	**LATE ADOLESCENCE** *Taking charge* ☐ I can describe what medications I should not take because they might interact with the medications I am taking for my health condition ☐ I am alone with the doctor or choose who is with me during a health care visit ☐ I can tell someone what new legal rights and responsibilities I gained when I turned 18 ☐ I manage all my medical tasks outside the home (school, work) ☐ I know how to get more information about IBD ☐ I can book my own appointments, refill prescriptions and contact medical team ☐ I can tell someone how long I can be covered under my parents' health insurance plan and what I need to do to maintain coverage for the next 2 years . ☐ I carry insurance information (card) with me in my wallet/purse/backpack.	☐ Remind patient and family that at age 18 the patient has the right to make his or her own health choices ☐ Develop specific plans for self-management outside the home (work/school) ☐ Provide the patient with a medical summary for work, school or transition ☐ Discuss plans for insurance coverage ☐ If transitioning to an adult subspecialist, provide a list of potential providers and encourage/facilitate an initial visit.

This checklist was based on faculty expertise, review of existing publications and adaptations of "Transition Planning Checklist" by the Children's & Women's Health Centre of British Columbia.

https://www.naspghan.org

Preaching to the choir?

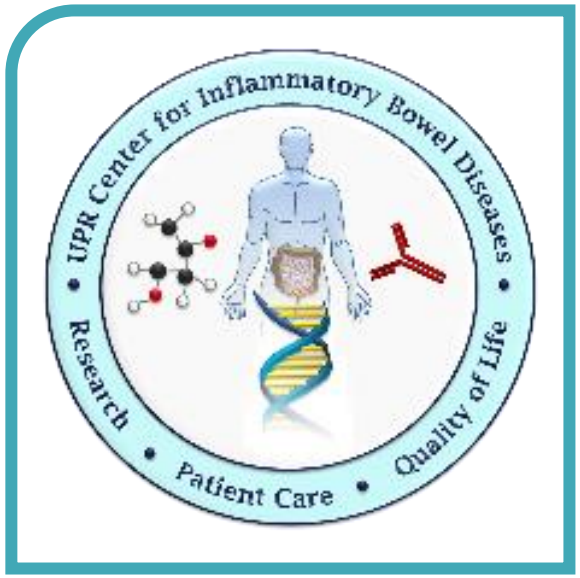
TABLE 2

Recommendations for Adult Gastroenterologists

Awareness that pediatric patients entering the adult healthcare system for the first time may not be fully prepared or aware of the differences between the two systems
Collaboration with the pediatric gastroenterologist and team prior to the actual "transfer" of care. Examples: participation in transition clinic, information sessions
Anticipate questions from patients about IBD, treatment plans and impact on body image, and sexual health
Educate the patient in understanding the adult health care system
For newly transferred patients the first few visits may require longer appointment times.
Anticipate that parents may want to continue to have a key role in their child's care and that patients may not be able to provide the complete medical history without their parents input. Although the goal is for patients to take on responsibility for their own care the process may be gradual.

Leung, Inflamm Bowel Dis 2011;17:2169-2173


CHICK



Thank you!
Questions?